Equip for Equality Comments
Draft of Illinois' Medicaid 1115 Waiver

Equip for Equality, the independent, not-for-profit organization designated by the Governor in 1985 to administer the federally mandated Protection and Advocacy system for people with disabilities in Illinois, appreciates the opportunity to submit comments to the draft application for the Illinois Medicaid 1115 Waiver. As we expressed in our comments to the Concept Paper, we support the vision of an Illinois Medicaid system that provides better outcomes for individuals with disabilities and gives more individuals the opportunity to access home and community based services. We continue to be concerned about certain aspects of the proposed waiver and comment on particular aspects of the draft application below.

General Comments

We understand that the state plans to defer decisions on many of the details of the waiver until the implementation phase, but we are still concerned about the astonishing lack of detail in the draft waiver application. Many of the most important elements of how the waiver will operate, including who will administer it, are simply not discussed in the waiver application. Even those elements that are discussed, such as budget neutrality, are presented in a much broader way than we would have anticipated or advised given the magnitude of transformation of the Medicaid program. We reiterate that it is crucial that stakeholders, including Medicaid recipients, be given an opportunity to review and comment on these details prior to implementation in order to ensure success of the program.

Home and Community Based Infrastructure, Coordination and Choice

We strongly disagree with the request that certain services delivered in "Specialized Mental Health Rehabilitation Facilities" (SMHRFs) be treated as costs not otherwise matchable to allow for crisis and acute inpatient reimbursement. Contrary to the representation made in the

draft application, the legislation that created SMHRFs was *not* passed in "an effort to transition a large number of individuals from nursing facilities to more community integrated settings". Rather, it was passed over the objection of many mental health advocates, including Equip for Equality, in an effort to keep current Institutions for Mental Diseases (IMDs) in business by allowing them to provide new services. It is problematic enough that these facilities, which serve as little more than warehouses for people with mental illnesses and many of which use restrictive and troubling privilege systems to prevent residents from exercising even basic freedoms like leaving the facility, now have expanded authority to provide additional services including triage, crisis stabilization, and "transitional living." The *Williams v. Quinn* Court Monitor expressed grave concerns about this legislation in one of his reports to the court, noting that it would take the state in the wrong direction and undermine its ability to comply with the Consent Decree. And as we have seen in reviewing records for numerous residents, these facilities are ill-equipped to stabilize people who are in crisis.

The draft application inaccurately portrays the SMHRFs as currently providing transitional supports, including crisis intervention and acute stabilization. The reality is that SMHRFs are not now providing these services and have absolutely no experience in providing them. Further, the services contemplated by the SMHRFs would be provided in the same large congregate institutions (IMDs) that have failed people with mental illness in the past State and federal funds are much better invested in more community-based mental health services as opposed to new investment in SMHRFs that have no expertise in providing these types of services and have an extremely poor track record of transitioning individuals back into the community.

More generally, although it has been stated that the 1115 waiver application does not include a restructuring or eliminating of services, including long-term services, that are offered to current waiver recipients, we remain concerned whether those who are currently receiving services to enable them to live successfully in the community will continue to receive those services. We understand that further details are to be worked out in the implementation process, but it is important to assure waiver recipients now that they can continue to control the services they receive and that this process will not result in an arbitrary change to their services.

The waiver application makes several references to individuals with disabilities receiving services in the most "appropriate" setting. We would urge the state to instead refer to the "most integrated" setting. Underlying this concept is the basic premise of the *Olmstead* decision: that an individual with a disability has the right to receive services in the place that is the most integrated setting capable of meeting their needs. The language used in the waiver should be changed to reflect this premise.

We are fully supportive of the concept and look forward to working with the state to develop flexible and creative options in order to be able to offer housing under the Medicaid program. We do want to emphasize that any housing option offered should be housing that is **integrated** into the community and allows individuals to fully experience the benefits of community living.

One of the components of the program that does not appear to be contemplated in the draft waiver application is the option for the state to de-link eligibility for home and community based services and nursing home services. The draft waiver application talks broadly about reducing institutional bias and increasing access to home and community-based services. De-linking the eligibility requirements for home services would allow individuals who need some

services in order to live in the community, but who do not qualify for a nursing home level of care, to receive services that will allow them to continue to lead healthy, independent lives. The state should explore this option and capitalize upon the federal government's stated willingness to allow states to de-link this eligibility by including it in the 1115 waiver.

Delivery System Transformation

We have already expressed our disagreement with the choice to use state and federal funds to provide debt relief for nursing homes that choose to downsize. We recognize that as more home and community based services are offered, it may be necessary for nursing homes and other long-term care facilities to downsize or close. However, we do not support the decision to use state and federal funds to assist this change. Beyond disagreement with the basic concept, the details that were laid out in the draft application seem to place sole responsibility for deciding how to use funds with the Department of Healthcare and Family Services (HFS). Given that this will result in a change in the availability of long-term services, HFS should be consulting with other state agencies that are responsible for ensuring delivery of services, including the Division of Developmental Disabilities and the Division of Mental Health of the Department of Human Services and the Department of Public Health. HFS should not make the decision about how to distribute these funds without consulting those agencies that are responsible for ensuring the adequacy and availability of the substantive services.

Workforce Development

We are fully supportive of using new and innovative ideas in order to encourage more individuals to be a part of the healthcare workforce, particularly in rural or other underserved areas. One concept that we suggest be incorporated into the workforce development initiatives is incentives for employment and training of people with disabilities. One of the goals of the

waiver is to "move the system away from facility-based sheltered work programs by promoting and fostering greater community-integrated, competitive employment opportunities." Encouraging the training and employment of people with disabilities to be a part of the healthcare workforce in various capacities and offering incentives for employing people with disabilities will further that goal.

Consistency with Federal Consent Decrees and Use of Consumer-Based Principles

Equip for Equality serves as co-counsel for people with disabilities in three federal community integration class actions – *Ligas v. Hamos, Williams v. Quinn* and *Colbert v. Quinn.* In all three cases, the state has entered into Consent Decrees that set forth the state's obligations and adopted Implementation Plans that provide for how the state will meet its obligations. It is imperative that the waiver application explicitly state that, for class members in the *Ligas, Williams,* and *Colbert* cases, the 1115 waiver will be implemented consistently with the Consent Decrees in those cases. We also believe the waiver needs to reference consumer-based principles that will maximize the participation and support of the individual in developing and implementing a person-centered plan that addresses the individual's needs and preferences.

In conclusion, we hope that you will consider our comments and we look forward to working with you as the process of transformation of the Illinois Medicaid system moves forward. If you have any questions or would like further information, please contact Melissa Picciola at 312-895-7328, melissa@equipforequality.org or Cheryl Jansen, cherylj2@equipforequality.org at 217-544-0464.